

Remarks of Henry A. Waxman, Chairman
Subcommittee on Health and the Environment
to the
Association for Retarded Citizens of the United States
1990 Governmental Affairs Seminar
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I'd like to speak to you this afternoon about 3 issues which I know are of major concern to you: Medicaid reform, the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act, and the Pepper Commission recommendations for long-term care.

Medicaid Reform

When I spoke to you last spring, I told you that a compromise Medicaid reform proposal had been developed, that it had support in the House, and that I would push for its enactment.

As you know, the Florio-Waxman-Dingell bill was approved by the Energy and Commerce Committee last July, and passed the House last October. Unfortunately, we were not able to persuade the Senate to accept it, and it was not among the Medicaid improvements included in the final Budget Reconciliation Act.

Last month, I joined Mr. Dingell and Mr. Tauke, and 28 other Democrats and Republicans in reintroducing the Medicaid Habilitation Services Amendments, H.R. 3934.

These are the same provisions that passed the House last year. The only difference is that the effective dates are moved back one year.

Under the bill, States would be given the option to offer community habilitation and supportive services to individuals with mental retardation. States would not have to demonstrate budget neutrality or limit the number of clients participating, as they now have to do under the home- and community-based care waiver.

The bill would strengthen the current requirements for intermediate care facilities for the mentally retarded in order to improve the quality of care and the quality of life for Medicaid clients.

The bill would also establish a level playing field for providers with respect to payment. While the bill would not specify the precise methodology a State must use, it would require that the State apply the same payment methodology to State-run providers and to providers operated by private nonprofit organizations like yourselves.

Finally, the bill would require States to make "fair and equitable" arrangements for employees at facilities that are closing or downsizing. These employee protections would include retraining and redeployment into community-based providers.

As was the case last year, our Committee won't be able to take up this legislation unless the Budget Committee sets aside some resources for new Medicaid spending. The Waxman-Tauke-Dingell bill is one of 6 major Medicaid initiatives that I and other Members have introduced. All but one of the other bills is, like H.R. 3934, left over from last year's reconciliation process -- infant mortality, child health, community care for the frail elderly, and hospice care. In addition, there is a new initiative to give the States the option of covering preventive drugs for individuals infected with the AIDS virus.

I am urging the Budget Committee to fund all of these initiatives. If the Budget Committee does not give us new Medicaid entitlement authority, my Committee will not be able to act.

We are not in a favorable budget climate. It will be difficult to fund any of the 6 Medicaid initiatives. But the Waxman-Tauke-Dingell bill faces some additional obstacles. The Administration is strongly opposed. The States are at best unenthusiastic, and some are strongly opposed. And, most critically, support for the bill is lukewarm.

As I told you last year, I wish we could mandate coverage of community-based services under Medicaid. The fact of the matter is that we can't. This compromise is the best we can do in the House.

I have to tell you that, unless support from you and other beneficiary advocates is more enthusiastic this year than it was last, we may not be able to overcome the opposition.

That would be a tragedy. We have to begin to correct the institutional bias in Medicaid. Giving the States the option of offering

these services is an important step in that direction. We can do it this year -- but only if you and other progressive groups push very hard.

Developmental Disabilities

Let me next turn to the Developmental Disabilities Act.

As you know, we will be reauthorizing this important legislation this year. I am now undertaking discussions with Representative Madigan, the ranking minority member of my Subcommittee. Mr. Madigan has been a strong supporter of this legislation in the past, and I am hopeful that we will be able to join on the same bill and move it forward on a bipartisan basis.

The Committee's work on health bills has been slowed by consideration of the Clean Air Act. However, I expect that the full Committee will conclude its Clean Air markup by the Easter recess. Shortly after Congress returns in mid-April, I intend to hold hearings on the Developmental Disabilities reauthorization.

I hope that we can continue to count on your advice and support as this legislation is developed.

Pepper Commission

Finally, let me turn to the issue of broad long-term care reform and its implications for individuals with mental retardation.

As you know, two weeks ago the Pepper Commission issued a series of recommendations on access to health care and long-term care for all Americans. The long-term care recommendations had strong, bipartisan support: only 4 of the 15 Commissioners dissented from the recommendations.

From your standpoint, the key element of the Commission's long-term care proposal is that severely disabled persons of all ages would be eligible for home and community-based care. Unlike Medicaid, this home and community-based care program would not be means-tested. It would be financed by the Federal government, but administered by the States under Federal guidelines.

Severely disabled people of all ages would be eligible. This includes two groups: individuals with severe cognitive impairments, and individuals who need hands-on or supervisory assistance with three out of five Activities of Daily Living: eating, transferring, toileting, dressing, or bathing.

Case managers would determine the number of hours of care and the mix of services each beneficiary would receive, based on an individual care plan. Operating within a budget set by the Federal government, the case manager would be responsible for assuring that the beneficiary received needed services.

The benefits available under this program would include personal care services, physical and occupational therapy, and respite services for caregivers.

As you know, none of the Commission's recommendations was unanimous, and some of them are quite controversial. What is striking about this particular benefit was the breadth of consensus around it. While there were some differences about programmatic details, I don't recall that any of the Commissioners argued against the basic proposition that we should make home and community-based services available for the severely disabled.

Now I don't want to suggest that this proposal is a complete solution to the needs of the individuals that you represent. There are a number of services -- prevocational, supported employment, day habilitation -- that are important to your population but would not be covered under the Pepper recommendations. Yet the basic building blocks that you've been trying to put in place -- case management, personal attendant care, and respite care -- are there. And once they are in place, they can be built upon.

The Pepper Commission also made recommendations regarding nursing home coverage. The nursing home benefit defined by the Commission would not address the needs of the populations that are now served by intermediate care facilities for individuals with mental retardation. Instead, the Commission assumed that the current Medicaid institutional benefit would continue.

Conclusion

It is unlikely that this new home health program, or the other Pepper Commission recommendations, will be enacted this year. The amount of new Federal dollars required -- \$43 billion for the entire long-term care package -- is simply too large for quick action.

But the Commission has launched a serious debate on health care and long-term care reform. Over the next few months, there will be hearings, discussion, debate. I hope that the next Congress, which convenes next January, will bring us enactment of these broader reforms.

In the meantime, I intend to continue to seek enactment of Medicaid reform. Compared with the kinds of numbers the Pepper Commission is projecting -- \$24 billion per year for the home care benefit alone -- the \$200 million-per-year cost of the Waxman-Tauke-Dingell bill looks extremely modest.

Make no mistake. We cannot afford to set aside the fight for Medicaid reform and focus all of our energies on the Pepper recommendations. The Medicaid reforms can be enacted this year. By giving us operational experience and better cost data, these incremental reforms can help to move us forward toward the enactment of broader reforms such as those proposed by the Pepper Commission.

This is a fight that can be won, but not without your help. I hope that I can count on it.